

Principles and practice of palliative care

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The relatively recent recognition that terminally ill patients suffer needless distress has led to the development of hospices and palliative care services for the dying. Now needed by those concerned with terminal care is a summary of the principles and practice of palliative care, and such was provided at an international seminar held in Montreal Nov. 3-5, 1976. Attended by more than 300 from all over North America, the seminar examined the state of the art of palliative care for the terminally ill and their families. Both the practical aspects of care and management of the dying patient and the theoretical and research basis of palliative care were discussed. The result was 3 days of intense but stimulating interchange of ideas.

The seminar was directed by Dr. Balfour M. Mount (director, palliative care service, Royal Victoria Hospital, Montreal). The faculty comprised staff of the Royal Victoria Hospital's palliative care service and others closely connected with it. Key speakers and resource persons were two internationally respected leaders in the field of terminal care: Dr. Elisabeth Kübler-Ross (Chicago, Illinois) and Dr. Ciceley Saunders (medical director, St. Christopher's Hospice, London, England).

Six aspects of palliative care were explored during the seminar: total care, symptom control, pain control, emotional needs of the dying, bereavement and grief work and staff support. This report is a summary of the state of the art of palliative care as reflected in the proceedings of the seminar.

The concept of total care

Patients with a progressive disease, said Saunders, need appropriate treatment *throughout* their illness. Treatment is appropriate if patients benefit from application of one of two complementary systems at the correct time: one concerned with eliminating a controllable disease, the other with relieving the symptoms of an incurable disease. Either must be available when needed; no patient should be "locked into" a system directed in what is, at a particular stage of the illness, the wrong course. A physician should no more provide aggressive treatment that cannot be effective and that is distressing and isolating than he should merely control symptoms when the underlying cause is still treatable or has again become treatable. When it becomes appropriate to extend a patient's life the emphasis should be on improving the quality of the life remaining.

It is unfortunately true, observed Saunders, that care of the terminally ill is not only inappropriate but also inept: the classic study by Hinton,¹ confirmed by the studies of Rees² and Cartwright, Hockey and Anderson³ clearly showed that the dying often suffer unnecessarily. A study from St. Christopher's Hospice yielded similar findings. Pain affecting patients in three groups was the criterion of suffering. Of patients managed at home 29% had severe and mostly unrelieved terminal pain; of hospital-based patients 20% had preterminal pain, unrelieved also after admission to hospital; but of patients referred to St. Christopher's Hospice only 8% had unrelieved pain, even though 37% of them had been in persistent pain before referral.

What are the principles of total care? Saunders has developed 13 such principles (Table I), emphasizing flexibility of their application according to the caring environment. These principles may be applied whether the patient is in a general ward, an oncology unit or a palliative care unit. Their application depends less on the technologic impedimenta of intensive care units than on personal, skilled care by staff of all disciplines. Such therapeutic principles should in fact underlie management of many patients now occupying beds in the "cure system" who are actually receiving inappropriate treatment. Moreover, if the basic principles of palliative care are followed, the terminally ill patient may be cared for entirely or partly at home — a state of affairs quite different from that in Canada today, where 70% of Canadians die in hospitals or other institutions.⁴

Wherever a patient is treated, the basic approach to medical care must be warm and personal, yet effective and efficient. Talking to the patient, learning about him as a person, answering his questions honestly and remaining accessible to him — and doing the same for the patient's family — are essential elements of palliative care that must complement treatment of the disease and its symptoms.

Personnel of palliative care units become skilled in the application of these principles. Consequently, such expert staff have an obligation to cooperate with others treating terminally ill patients and to encourage interest in and development of the principles of palliative care, so that all patients — whether treated in an acute general ward, an

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acute special unit, a chronic care unit or institution, or in the home — may benefit from the lessons learned in palliative care units or hospices.

Treatment, whether curative or palliative, urged chemotherapist Dr. Peter H.S. Geggie (department of medicine, Royal Victoria Hospital, Montreal) must be thorough. If it is appropriate, curative therapy must be effective, even aggressive: there is a 70% chance of remission for 18 months in patients treated with chemotherapeutic agents (untreated patients survive for an average of 2 months). When it is decided that curative and life-prolonging goals are inappropriate, the physician's responsibility remains, albeit directed differently.

Palliative care is total care in three respects: attention to the physical, emotional and spiritual needs of the patient; care in an appropriate environment, supported by auxiliary services such as social work; and supportive understanding of the needs of the patient's family. Recognition of the principles underlying total care is growing as is that of the need for research, teaching and experience in terminal care. Studies now must include careful monitoring of clinical experience and should provide, for example, information from controlled clinical trials of analgesic and cytotoxic agents, from investigation of psychosocial aspects, and from a firmer, more detailed understanding of the practice of symptom control.

Symptom control

"Before all else," Mount has written,⁵ "palliative care must mean excellent symptom control, achieved by a health

care team skilled in clinical pharmacology." By providing expert control of symptoms, including pain, those caring for the dying can pursue an active treatment course that is the antithesis of the abandonment of hope and help implicit in the all-too-common dictum, "There is nothing more we can do." In addition, effective symptom control counters a tendency to concentrate on the psychologic aspects of treatment; as Dr. John Scott (physician, palliative care service, Royal Victoria Hospital, Montreal) cautioned, "We mustn't make death into a psychiatric illness."

The two chief bases of palliative care, good medical care and good nursing care, are essential to good symptom control. For physicians, as Dr. Sylvia A. Lack (medical director, Hospice Incorporated, New Haven, CT) suggested, the keys to successful treatment of symptoms are the familiarity with, and the application of the same degree of expertise to, symptom control that would mark successful diagnosis.

Symptoms may arise from any organ or system. Symptoms often change — and in this respect, Scott pointed out, terminal care differs from chronic care. Furthermore, symptoms may vary from excruciating pain to indefinable weakness, and each requires appropriate palliative therapy. The correct approach is to define the cause of the symptoms so as to exclude those that may be caused by a remediable disorder, to take trouble in treating seemingly minor symptoms and to treat effectively (in the case of drugs, respect them but be bold in their use, advised Scott).

A wide variety of symptoms can be treated, yet physical symptoms are

treated inadequately;⁶ however, as Geggie stressed, "A good deal can be done with good care." Consider just three general symptoms — weakness, anorexia and thirst. *Weakness* may be managed by a) preventing fatigue (e.g., by means of handrails, a commode, a walker, an adjustable bed, monkey bars), b) utilizing the services of a physiotherapist (e.g., for passive exercises and positioning of the patient), and c) prescribing prednisone, 5 mg *tid* if weakness is nonspecific or associated with hypercalcemia. *Anorexia*, rather than being simply but negatively ascribed to malignant disease and thereby dismissed, may be treated by a) serving frequent, small but attractive and nutritious meals, b) offering appetizing snacks (a blender and a microwave oven are invaluable for this purpose), and c) ensuring adequate mouth care (Table II). *Thirst* can be alleviated by a) giving frequent sips of an acceptable liquid and b) attending to mouth care (intravenous therapy is not favoured, in part because it is seldom necessary).

The approach taken to control of gastrointestinal and respiratory symptoms is illustrated in Table II. Details of control of specific symptoms originating in other systems are provided in a recent report by the Royal Victoria Hospital, Montreal.⁵

Treatment of pain

Perhaps because persistent pain is so debilitating and demoralising — Saunders' term of "total pain" points to its all-consuming nature — the control of pain is frequently the key to good palliative care. Pain can be con-

Table I—Basic principles of palliative care (Saunders).

Principle	Comment
1. Treatment of variety of patients in differing environments (e.g., day centre, half-way house, geriatric facility)	"High-person, low-technology" approach
2. Management by experienced, multidisciplinary team	Free, effective consultation between numerous specialists essential
3. Expert control of common symptoms, especially pain	Development of skills and research mandatory
4. Skilled, experienced nursing	Stable team with varied background and talents (use trained nurses with short periods of experience plus auxiliaries and part-time staff for longer service)
5. Interdisciplinary team led by appropriate member for individual patient	Cooperation, coordination among staff and common sense of purpose and development as therapeutic community a key
6. Concern for patient and family as unit of care	Concern before, during and after stay in palliative care environment
7. Volunteers as integral part of caring team	Various talents available among volunteers from widely differing backgrounds foster personal links with community
8. Effective home care	Program developed according to local circumstances and integrated with palliative care service
9. Approachable central administration	Unobtrusive efficiency helpful to staff, patients and families; as many "safety valves" as possible are necessary
10. Bereavement follow-up	Identification and support of survivors in special need; coordination with local services or resources essential
11. Research, methodical recording and statistical analysis of findings	Purpose: evaluation and monitoring of clinical practice and experience and other forms of research directed to establishment of soundly based practice in all areas of operation and teaching
12. Teaching	Particularly for disciplines of medicine, nursing, social work, theology
13. Commitment	Inevitable involvement in sometimes painful work requires maturity, objectivity blended with compassion, understanding

Table II—Guide to control of specific gastrointestinal and respiratory symptoms*

System, symptom	Therapy
Gastrointestinal	Discontinue or decrease phenothiazines, tricyclics, antihistamines
Dry mouth	Mouth washes <i>q2h</i> Give lemon candies, pineapple chunks, artificial saliva Remove foreign objects from mouth Treat candidiasis (nystatin oral suspension) and stomatitis secondary to chemotherapy with astringent washes or washes containing topical anesthetic
Dysphagia	Eliminate nonessential drugs Prefer liquid or suppository forms of drugs, or crush tablets and mix with ice cream, honey etc. Diet: small, frequent liquid or soft-food feedings Honey solutions, fizzy drinks (counteract waterbrash of esophageal cancer)
Nausea, vomiting	Give antiemetics regularly a. Phenothiazines (prochlorperazine, 5–10 mg <i>q4h</i> ; chlorpromazine, 10–25 mg <i>q4h</i> ; methotrimeprazine, 5–10 mg <i>tid</i>) b. Antihistamines (cyclizine, 50 mg <i>tid</i> ; dimenhydrinate, 50–100 mg <i>q4h</i>) c. Metoclopramide (Maxeran), 10 mg <i>tid</i>
Constipation	Control and prevention a. Any patient on narcotics takes dioctyl sodium sulfosuccinate (1 to 3 caps <i>bid</i>) and Senokot (1–3 tab <i>bid</i>) b. Other drugs: Dulcolax, bisacodyl, Dorbane c. Bran (for bulk, but may irritate); Serutan Treatment: Suppositories, enemas, disimpaction
Diarrhea (commonest cause: overflow around fecal impaction)	Review drugs Chalk compound (e.g., Kaopectate) Narcotic: Lomotil (1–2 tab <i>q4h</i>) or opium compounds
Bowel obstruction	Early in disease: Nasogastric suction, IV \pm colostomy Late in disease: a. Antiemetics (<i>qv</i>), IM first, PO as soon as possible b. Analgesics — IM morphine first, then Brompton mixture or Lomotil for peristaltic cramping c. Stool softener — e.g., Colace <i>bid</i> c. Oral fluids and soft diet if vomiting limited
Respiratory	
Dyspnea	Calm, quiet reassurance with frequent observation Proper positioning in bed or reclining chair Mouth care Oxygen Thoracentesis \pm instillation of chemotherapeutic agents for pleural effusion of advanced malignant disease Anxiolytics for pain with attacks, anxiety Systemic steroids for lymphangitic metastasis Narcotics
Cough	For expectoration: physiotherapy, hydration For suppression: Lindus codeine (5–10 ml <i>q4h</i>) or morphine if this is given for pain
Bronchospasm	Bronchodilators: a. Oxtriphylline (Choledyl, 200 mg <i>qid</i>) b. Salbutamol (Ventolin, 1 tab <i>qid</i> or inhalations) c. Theophylline ethylenediamine (Aminophylline) PO, IV or suppos.

*Attention must always be paid to underlying premorbid conditions also.

trolled when an interdisciplinary team attacks the physical, social, psychological and spiritual components of pain in a milieu that is supportive of the patient.

The aims of treatment of intractable pain, as described by Mount, Ajemian and Scott,⁷ are as follows: determination of the cause of pain, prevention of pain rather than treatment as it occurs, erasure of the memory of pain, restoration of an unclouded sensorium and a normal affect, and ease of administration of therapy. Although there are many available nonpharmacologic forms of therapy, the pharmacologic approach is the most useful in palliative care. Hypnotics, anxiolytics, major tranquilizers and tricyclic antidepressants have their place, but "it is the appropriate choice and careful dose titration of analgesics which is crucial to pain control".⁵

Many analgesics, which can be given in different forms and by different routes, can be used;⁸ the principle is to titrate the dose of the selected analgesic against the patient's current requirements. Whatever analgesic is used, doses should be administered at regular intervals to prevent onset of pain and to erase the memory of pain. For most patients the oral route is practical until the final few days or hours, so that some care is possible for all or much of the terminal period for many patients.

The Brompton mixture, long used in Britain, is now becoming accepted in North America in the treatment of pain for terminally ill patients. Its value has been well described by Mount, Ajemian and Scott⁷ and its efficacy in cancer patients has been analysed by Melzack, Ofiesh and Mount.⁹ At the Royal Victoria Hospital, Montreal the

standard mixture contains 10 mg of morphine, 10 mg of cocaine, 2.5 ml of 95 to 98% ethyl alcohol, 5 ml of flavouring syrup and chloroform water to 20 ml; the morphine content can be varied. A phenothiazine such as prochlorperazine, 5 mg in 5 ml, should be given concurrently; this may produce antiemetic, anxiolytic and narcotic-potentiating effects. The great advantage of the Brompton mixture is that careful adjustment of the dose permits a pain-free state without sedation. Pain is then no longer all-consuming.

Emotional needs of the dying

A student nurse who had a terminal disease wrote that "the dying patient is not yet seen as a person and thus cannot be communicated with as such".¹⁰

She perceived and verbalized the gap between the patient and the caring staff; in addressing the physician and nurses looking after her she wrote of her main needs:

I know you feel insecure, don't know what to say, don't know what to do. But please believe me, if you care, you can't go wrong. Just admit that you care. That is really for what we search... Don't run away — wait — all I want to know is that there will be someone to hold my hand when I need it. I am afraid...¹¹

Saunders summarized the emotional needs of the dying in three requests made by them: "Don't leave me", "Listen to me" and "Help me". Dying patients feel increasingly isolated as their world contracts; a primary goal of palliative care must be to alleviate the sense of isolation felt by the terminally ill.

A unique study¹² of the needs of the dying was reported by Robert W. Buckingham III (research director, Hospice Incorporated, New Haven, CT), who observed the needs of the dying while assuming the role of a patient with cancer of the pancreas. As a participant observer Buckingham confirmed the desire of the terminally ill patient to be regarded as a person as well as a patient.

Important to the morale of patients in hospital is a patient-to-patient support system, which relays the strength from one patient to another, as person to person rather than patient to patient. Similarly the patient-as-person is supported by care given by the patient's own family and by student nurses and volunteers, which the Royal Victoria Hospital's palliative care unit fully encourages.

The patient, like any healthy person, is a giver — but, as Buckingham found, a hospital's environment and organization does not allow the patient to give. He is surrounded by personnel who are giving as part of their daily duties, yet he cannot give because he is recognized as a patient rather than a person: when he is admitted to hospital his social status is shed; his clothes are shed as he assumes the sick role; and communication between staff and patients is often discontinuous and indirect (as a small example, Buckingham found that, in the general surgical ward, medical staff rarely looked patients directly in the eye). Buckingham's observations led him to conclude that not only do patients want to give but also their experiences of disease constitute remarkable teaching material; the role of the patient-teacher, Buckingham asserted, has great potential for the medical profession.

The role of the patient as teacher has been recognized by Saunders and

Kübler-Ross, both of whom have been much concerned with the dying. How should one work with the dying? According to Kübler-Ross, anyone caring for a dying patient must do so from his view as a person rather than an impersonal role-player; it is an attendant's personal strength and assets that the patient, in seeking fulfillment of his needs, draws strength from. One must also look for the patient's own strengths and assets; these can be used to emphasize a patient's positive attainments, good memories and those daily experiences that may be pleasant. One must look for the things that are common to both patient and physician, for the things that unite one another.

Each patient is a different person; each physician is a different person too. How each physician helps each patient is an individual matter, but the traditional virtues of kindness, honesty and simplicity on the part of the physician will help him go far to help the dying patient fulfil his emotional needs.

Bereavement and grief work

Attention to the needs of the deceased patient's relatives is an important aspect of the work of a palliative care service. Kübler-Ross stressed the importance of helping relatives overcome the stresses of bereavement.

Kübler-Ross emphasized the need to help the dying patient bring into the open and discuss "unfinished business". This serves not only the patient himself before his death, but also his relatives, in whom later grief work is facilitated. Resolution of grief is important. The risk of unresolved or abnormal grief reaction is particularly high for certain persons in three settings: relatives of a person whose corpse cannot be found after death (e.g., when the corpse is lost at sea or in war); relatives who have been informed of a patient's death by someone other than a physician; and parents of children who have died young. Among the third group, Kübler-Ross noted, 75% of parents were on the verge of separation 1 year after the child's death because "spouses are out of phase with each other" at this time; she advised that "spouses must be allowed to explode together".

Also of value is the help of volunteers who themselves have experienced bereavement. Staff and relatives can help relatives share their feelings of loss, Kübler-Ross explained, with someone "who has been that route before". They can help plan the practical details of the funeral, for example, and, at follow-up 4 weeks later, they can answer questions not thought of earlier.

Saunders elaborated on "the long way you have to travel after bereavement" and the approach taken at St. Christopher's Hospice. Grief work begins during the terminal illness. At St. Christopher's families, especially spouses, are encouraged to spend as much time together as is feasible in pleasant surroundings, and photographs may be taken of the family together before death; such measures are helpful in grief resolution. Also encouraged is the support given by understanding staff and patients.

Grief work continues after the loved one's death. At St. Christopher's the bereavement service keeps in touch with families for as long as seems necessary; listening, emotional support and other forms of assistance aid relatives. Relatives are welcomed back to St. Christopher's; a card inscribed with a simple message, "We are remembering you", sent to relatives on the anniversary of a patient's death is typical of St. Christopher's concept of total care.

The palliative care service of Montreal's Royal Victoria Hospital has adhered to the principles developed at St. Christopher's. Dr. A. Beszterczey (consultant psychiatrist, palliative care service, Royal Victoria Hospital, Montreal) summarized the work carried out there on bereavement and said that identification of "key persons" likely to be most affected has been an important element of bereavement follow-up. Bereavement follow-up must be active and it must be conducted professionally.

Beszterczey found that at the end of a 6-month bereavement follow-up period, active help for key persons lessened anger and guilt and improved health in a group of subjects aided by

Table III—Comparison of health of relatives of persons dying after treatment by palliative care service (PCS) and of relatives of those not so treated (control group)*

Symptom	Nos. of patients with symptoms	
	PCS group (n = 22)	Control group (n = 19)
Insomnia	22	19†
Deterioration of health	10	17
Decrease in appetite, weight	15	17
Pining, seeking	7	14
Hyperactivity	5	2

*Telephone enquiry at 6 mo after the death.
†Statistical significance levels (Fisher's test): for insomnia and hyperactivity, not significant at 5% level; for health deterioration, difference between two groups significant ($P < 0.01$); for other two sets of symptoms, difference significant ($P < 0.05$).

the palliative care service compared with control subjects who had not received such aid (Table III). The main reasons for the poorer health in the control group appeared to be lack of preparation of relatives through withholding of adequate prophylactic management, unfeeling or even callous management of relatives by medical staff, and lack of communication between staff and relatives.

An active bereavement follow-up is much appreciated by relatives, most of whom can be guided to recovery of physical and emotional health and reorganization of their lives by the end of the first year after their loss.

Staff support

Palliative care is demanding work; as Kübler-Ross commented, only if a palliative care unit staff is at harmony with itself can it succeed. Staff support is therefore important. Excellent staff training, smooth communication patterns and recognition and concern for staff emotional stresses appear to be key considerations for those organizing and administering palliative care services.

Professional stress in the care of the dying by staff of the Royal Victoria Hospital's palliative care service was studied by an independent team from the community resources service, Clarke Institute of Psychiatry (Dr. A. Lyall, J. Rogers, RN and M. Vachon, RN). Stress was first apparent 3 months after the palliative care unit opened; the general level of stress experienced by the unit's nursing staff was twice as high as that for staff in two other units of the hospital — and about half that experienced by a group of patients being treated for breast cancer. The degree of stress declined later, in part because some of the early palliative care staff resigned, leaving only the committed and dedicated "veterans". It would be helpful to identify types of persons who do well in such work; optimal qualities for staff, however, remained ill defined.

Among staff who did not resign two factors seemed important: the meaning of religion to them (no one who stated that religion was very important resigned) and a venturesome and spontaneous personality. These factors are compatible with the nature of palliative care work, which is unique and innovative and calls for an unusual degree of dedication and commitment demanding thereby acceptance of personal risk in giving of oneself to others.

The Toronto team also observed in palliative care staff the desire to fulfil an idealistic role with high expectations, attraction to a dedicated leader and welcome acceptance of autonomy

and lack of hierarchy in the service. These positive aspirations, however, were at times counterbalanced by negative realities — for example, the increased stress imposed by a nurses' strike and the lack of understanding of palliative care service objectives. Blurring of traditional professional roles, the absence of models in the form of similar units in other general hospitals and the stress in balancing caring involvement and detached objectivity in staff-patient relationships added other stresses. Besides, psychological factors motivating staff to work in the palliative care service may have had their own implications.

Insight into psychological problems imposed by work with the dying can be developed with help of a staff psychiatrist. Beszterczey noted that staff stress could be considered from the perspectives of phase-specific stress and situation-specific stress. The former type of stress arose from the development of the palliative care project, a new and unique service; the latter, from the need to confront specific circumstances encountered on the palliative care service, which too were unique. The Royal Victoria Hospital's palliative care service has been an innovative pilot project, easily seen on the one hand as a crusade by those working on the service and on the other as a hospital care phenomenon by those visiting the service from the rest of the hospital and from elsewhere, so that the staff were as goldfish in a bowl. Add to these factors overinvolvement with patients soon to die and exposure to intense affective experiences (in the first 18 months an average of three patients died weekly) and the need for psychiatric staff support became evident.

The opportunity for staff to ventilate and understand their feelings has been central to the effective operation of the Royal Victoria Hospital's palliative care service. A staff support system must serve the personnel of the service — this can be done at regular meetings, with the advice and assistance then and at other times by the staff psychiatrist, by palliative care service physicians and by the service social worker — and it must also support the service's own activities, particularly educational (e.g., teaching the elements of what is a new area in medicine and using library resources) and social (e.g., get-togethers to relieve stress and promote understanding of colleagues in the service). Such a support system is essential if a palliative care service is to function harmoniously. The ultimate support system, however, as Beszterczey observed, lies within ourselves. A priority task for research in palliative care must be the continued development and re-

finement of staff selection criteria and support systems.

Conclusion

The concept underlying palliative care is in fact an old one, as witness the adage "to cure sometimes, to relieve often, to comfort always". In part, certainly, the emphasis in palliative care lies in providing overall comfort for the dying patient, but much more is involved. It is necessary to be concerned with the person as well as the tumour and, as Saunders has said, with the need to affirm the person in the patient and to bring to the aid of the patient with a terminal disease the many elements of total care that, in a technologic age, may be obscured by the chrome and plastic finish of medicine today. Good medical care, skilled nursing, understanding pastoral care, use of auxiliary services such as physiotherapy, social work and home-care programs, acceptance of the help of volunteers and patients' families, attention to the needs of families also — these are the elements of total care that must be developed in providing competent palliative care. The growing interest in palliative care perhaps represents an adjustment of the balance of the pendulum swinging between medicine's art and science, so that a patient can ask of a physician, "Let me die", not "Don't kill me" — and the physician can agree, knowing that indeed to everything there is a season.

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